

Joint Advisory Committee (JAC) (Newborn Screening and Follow-up)

JOINT ADVISORY COMMITTEE GUIDELINES

ARTICLE I

Section 1 - The name of this committee shall be **The Joint Advisory Committee (JAC) for the identification and management of children with conditions detected through newborn blood spot screening.**

ARTICLE II

Purpose and Authority

Section 1 - The JAC, established in 1993, has the purpose to ensure that the policies and programs offered by the State of Maine, Newborn Screening Program and Children with Special Health Needs Program, to improve the health and well-being of those individuals identified with certain suspected and confirmed disorders of metabolism, endocrinology and/or hemoglobinopathy are appropriate and effective.

Section 2 - The Committee has the authority to:

- Recommend rules, regulations, and standards to the State of Maine Health Officer for the detection and management of said disorders. This may include changes to the screening panel.
- Recommend policies and procedures for comprehensive follow-up treatment.
- Recommend policies and procedures for the care of families/individuals with false positive screening results.

ARTICLE III

Membership

Section 1 - Membership on the JAC may include, but not be limited to, voting members from the following groups; public health nursing, social work, practicing pediatrician; specialty physicians who have expertise in the diseases being screened for or under consideration for screening, dietitian, neonatologist, medical ethics; birth hospital nurse; a birth hospital quality assurance professional and at least four consumers. At least one consumer representative should be a person having one or more family members with a disorder being screened for by the newborn screening program or a person living with a disorder being screened for; one of the consumer representatives should not have a condition that is screened for or have a close family member with such a condition. Representatives from the community, professional organizations and non-profit groups that support health issues of newborns, children and their families may also be included as members. The Committee should be limited to 12-20 members

Section 2 - Appointments will be made by the Director, Bureau of Health or Director, Division of Family Health.

Section 3 - Geographic representation will be considered in making committee appointments.

Section 4 - Suggestions for new members may come from current members or the Bureau of Health.

Section 5 - Members will serve for two-year terms. Terms may be consecutive at the discretion of the appointing official. New members will begin their term in the January, although vacant positions need not wait to be filled. New members will be provided with an orientation packet and discussion with the Committee Chairperson or Program Director(s).

Section 6 - Responsibilities: It is recognized that each member brings to the Committee skills and knowledge that represent the State of Maine; therefore, it is expected that each member actively participate in Committee meetings by providing input on:

- issues concerning newborn blood spot screenings;

- policies and procedures concerning comprehensive treatment;
- educational related issues
- family needs; and other issues as appropriate.

Section 7 - Members should participate in all meetings: in person, by teleconference, conference call, if possible, or by submitting written comments.

Section 8- At the discretion of the Bureau of Health, members are considered withdrawn after non-participation for two consecutive meetings.

ARTICLE IV

Leadership

Section 1 - **Chairpersons**: The Chairpersons of the Committee shall serve for a one-year term. The Co-Chairs will be selected from member volunteers and affirmed by the membership and the Bureau of Health.

Section 2 - Responsibilities of the Chairpersons include, but may not be limited to:

- Presiding over meetings
- Determining the agenda in collaboration with the Directors of CSHN and Genetics/NBSP.
- Responsible for facilitating consensus on recommendations to the Department and its Programs.

Section 3 - Program Staff will provide support to the Chairpersons as needed by:

- Distributing agenda and materials.
- Arranging meeting location and specific needs based on agenda.
- Providing program perspective to discussions.
- Recording and distributing minutes.

Section 4 - Program Directors will act as facilitators at meetings.

ARTICLE V

Meetings

Section 1 - Regular meetings of the Board shall be held four times per year.

Section 2 - The Chair shall, in consultation with the State of Maine, Bureau of Health, have authority to convene meetings outside the regular meeting schedule for the purpose of conducting special sessions that are deemed necessary.

Section 3 - Committee meetings are open to the public. Notice of meetings will be provided on the program web site (in development) and through provider clinics and/or interested parties list.

Section 4 - Non-members will not have any voting privileges but may provide input and/or comment when recognized by the chairperson. Non-members shall be excused during discussions of a confidential nature, such as review of a specific case record.

ARTICLE VI

Decision-Making and Voting

Section 1 - The issue being discussed will determine decision-making process. The question or statement of the issue needing a decision or action will be clear and specific. Various decision-making models are available for consideration and are attached in the appendix.

Section 2 - As appropriate, the Committee will strive for consensus or modified consensus. Members shall indicate their response in visual manner or verbally.

Section 3 - The majority of members present at the meeting shall determine all questions.

Section 4 - For policy recommendations, three quarters of voting membership shall be required for a quorum. In the event that there are less than three-quarters of members present, decisions/recommendations will be tabled pending input or voting of absent members. Such input or voting may occur following the meeting by phone or electronically to Co-Chairs or Program Directors.

Section 5 - Program Directors are not voting members of the Committee. The Bureau of

Health MCH Medical Director, a representative of the Children with Special Health Needs Program and the Newborn Screening Program should be present to give Bureau and Program perspectives but also will not be voting members of the Committee.

Section 6 - Committee recommendations shall be presented to the Department of Human Services, Bureau of Health.

Section 7 - The final decision for program policies and activities resides within the Department of Human services, Bureau of Health administration.

ARTICLE VII

Committees

Section I - Ad Hoc Committees - Any committee temporarily needed to carry out activities may be convened at the discretion of the Chair or the Bureau of Health. Examples of such activities include; review of policies, collection of information, formulation of materials etc. Such committees shall cease to exist at the completion of the stated purpose.

Section 2 - It is anticipated that the need may arise to include members of other disciplines to accomplish the goals of the committee; therefore non-voting members may be invited to participate in meetings, activities and/or to provide input to the JAC.

ARTICLE VIII

Amendments

Section 1- These guidelines will be reviewed at the first meeting of the calendar year.

Section 2 - Guidelines may be amended after discussion and with approval of the membership and Department of Human Services, Bureau of Health.

Current Board Members

R.Stephen Amato, MD, PhD
EMMC- Pediatrics(Genetics/metab)

Valerie Banks, MS

MPSG- Genetic Counselor

Thomas Brewster, MD

Greater Portland Pediatrics

Ana Cairns, MD

Maine Pediatric Specialty Group (MPSG-CF Clinic) (Portland)

Mary Ellen Corrigan, MSN, CPNP

MPSG—CF Clinic

Mary Ann Gordon

Parent

Cathy Hamilton

Parent

The Reverend Arthur Kingdon (Vassalboro)

Nola Metcalf, RNC

Penobscot Bay Medical Center

Jerry Olshan, MD (Endocrine)

Maine Pediatric Specialty Group (Portland)

Connie Roy (Co-Chair)

Parent

Sarah Savage, MS

EMMC- Genetic Counselor

Sharon Schulberger

Dir. of Program Services March of Dimes

Gretchen Shantar, MS, RD, LD (Co-Chair)

Metabolism Clinic Coordinator

Barbara Bush Children's Hospital

Program Staff:

Wendy Smith, MD(Co Chair)

MPSG (Genetics/Metabolism) (Portland)

Daniel B. Sobel, MD

Maine Medical Center- Neonatology

Deborah Tuttle

Parent

Ellie Mulcahy, RNC
Genetic's Program
Maine CDC ,Division of Family Health

Toni Wall, MPA
Children with Special Health Needs, Director
Maine CDC, Division. of Family Health,

Coordinator (Vacant)
Newborn Screening Program, Coordinator
Maine CDC ,Division of Family Health

Amy Peaslee
Medical Secretary
Maine CDC, Division of Family Health

Ad Hoc Members:

John Kruegar
Director Public Health &
Environmental Lab

Anne Rossi, MD (Hematology)
Maine Children's Cancer Program &
Maine Hemophilia & Thrombosis Center (Scarborough)

Heather LeClerc, RD
Diabetes & Nutrition Center (Bangor)

Kelley Bowden, NNP
Maine Medical Center,
Perinatal Outreach Program

Next Scheduled Meeting Date

Sept. 17 and Nov. 19